

HIV/AIDS

WORK GROUP ON HEALTH CARE ACCESS ISSUES

for
American Indians/Alaska Natives

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American Indian
Alaska Native Work Group
on Barrier to HIV Care

Embassy Suites Hotel, Crystal City, Virginia
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Executive Summary

The Health Resources and Services Administration, Bureau of Health Resources Development (BHRD), sponsored an American Indians and Alaska Natives Work Group on Barriers to HIV Care on April 28 and 29, 1992. Twenty-one American Indians and Alaska Natives, as well as Federal representatives, met to discuss access issues related to providing HIV/AIDS services to American Indians and Alaska Natives. The work group, representing a diverse spectrum of American Indian traditions, helped the BHRD understand issues related to American Indians' access to HIV/AIDS services funded under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and begin to design evaluation projects to improve access.

The work group participants identified several cultural and logistical challenges to providing effective HIV/AIDS services within the American Indian and Alaska Native communities. The main considerations they identified were:

- The HIV/AIDS epidemic is only one of many serious health problems for American Indians. To be credible, any response to AIDS must be addressed within a larger context of public health issues.
- The sovereignty of First Nation peoples raises issues concerning State versus Federal funding.
- For many American Indians, HIV/AIDS is subordinate to issues such as food, housing, employment, and child or elder welfare.

The following categories of emerging issues and trends were enumerated and require attention to improve the quality of health care delivery for American Indians.

- Create literacy and culturally appropriate, accessible, and coordinated health services to address a wide range of physical and mental health problems within American Indian communities.
- Address issues related to sexuality, including sexual abuse, early sexual activity, dual sexual identity, and safer sex.

- Increase funding for HIV/AIDS and other health programs through a variety of sources.
- Increase community involvement in all stages of service delivery, from planning to the implementation of services.
- Arrange for technical assistance in seeking and administering funding, building coalitions, improving communication skills, and implementing HIV/AIDS service.

List of Acronyms

ACTG	AIDS Clinical Trial Groups
AIDS	Acquired Immunodeficiency Syndrome
ASO	AIDS Service Organization
AZT	Zidovudine
BCHDA	Bureau of Health Care Delivery Assistance [since July 1, 1992, renamed Bureau of Primary Health Care (BPHC)]
BHRD	Bureau of Health Resources Development
BIA	Bureau of Indian Affairs
BPHC	Bureau of Primary Health Care
CDC	Centers for Disease Control and Prevention
CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act of 1990
dDi	Dideoxyinosine (an anti-viral medication used for HIV)
ETC	Education and Training Center
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
IHS	Indian Health Service
NIDA	National Institute on Drug Abuse
NIH	National Institutes of Health
PWA	Person (or people) with AIDS
RFA	Request for Applications
RFP	Request for Proposals
STD	Sexually Transmitted Disease
SPNS	Special Programs of National Significance

Introduction

OPENING PRAYER

Indians say thank you for what we are going to have. Indians have good vision for the things they do. Smell all the good things in life, hear all the good things in life, and then talk about all these good things as a way of life because life can only come from life. Welcome all the powers of the world within the things that fly, the things that crawl, the things that walk on twos and fours, the things that live in the water, the ground, the valleys, on top of the mountains, and out on the plains. Things do not come unless we ask and so much will be revealed.

The Health Resources and Services Administration (HRSA), Bureau of Health Resources Development (BHRD), sponsored an American Indians and Alaska Natives Work Group on Barriers to HIV Care on April 28 and 29, 1992. Twenty-one American Indians and Alaska Natives, as well as Federal representatives, met to discuss issues related to the provision of and access to HIV/AIDS services. Although the work group members came from diverse American Indian heritages, it was only partially representative of the many American Indian cultures and groups. However, the 21 participants shared a commitment to improving access to HIV care for American Indians and Alaska Natives.

The objective of the work group was to understand access issues, identify key evaluation topics, and draft designs for potential projects. The participants were asked to help the BHRD:

- understand issues related to American Indians' access to HIV/AIDS services funded under the Ryan White CARE Act;
- propose evaluation project designs;
- improve access; and
- identify areas for technical assistance.

As part of the follow-up to this session, BHRD will help CARE Act program managers incorporate insights from participants and thus help grantees improve their response to American Indians' HIV needs. BHRD is working with other Federal agencies, including the Indian Health Service (IHS), to develop effective systems for delivering HIV care to First Nation communities and individuals.

Paul Ortega, a traditional medicine specialist from the Indian Health Service marked the session with a customary opening ceremony, followed by a welcome from Moses Pounds and Shelia Hunt Brayboy of HRSA. They described the purpose, format, and scope of the meeting. Participants introduced themselves and expressed their personal concerns and those of the group that they represented about access to HIV/AIDS services. BHRD Director, G. Stephen Bowen, provided an overview of the Ryan White CARE Act. The group briefly discussed the barriers to Titles I and II services experienced by American Indians and Alaska Natives. To define further the purpose and scope of the meeting, additional informal discussion took place at the dinner that followed.

April 29 began with a customary opening ceremony, followed by a talking circle, an American Indian process for ensuring that those who speak do so carefully while the others listen respectfully, without interrupting. During the talking circle, the work group identified four topic areas to recommend for research studies. The participants divided into four breakout groups. Each discussed an issue and reported back with preliminary recommendations. The work group ended with the conveners describing the process for communicating among participants and the follow up that would be required for evaluating the issues raised and the technical assistance needs identified.

This summary is organized as follows:

- Section I - an overview of HIV/AIDS programs, including the Ryan White CARE Act.
- Section II - the social and cultural context of health for American Indians and Alaska Natives.
- Section III - barriers to health care and support services.
- Section IV - perceived gaps in health care delivery.
- Section V - issues, concerns, and recommendations to be considered in administering the Ryan White CARE Act.

- Section VI - recommendations for evaluating study designs of research issues.

This summary report uses the terms "American Indians" and "Alaska Natives" as recommended by the participants. These are collective terms and not ones that people from the indigenous societies and cultures use to refer to themselves. There is not unanimous agreement among all indigenous peoples about satisfactory collective English terms. Whenever "American Indian" appears alone, it should be understood that the indigenous people of Alaska are also included.

The quotations, originating from the work group, were used to illustrate various points in this summary and are from notes taken by staff.

I. Overview of HRSA's HIV/AIDS Programs

TITLES I AND II OF THE RYAN WHITE CARE ACT

This overview, presented by Dr. G. Stephen Bowen, BHRD Director, explains Titles I and II and highlights additional aspects of the CARE Act. A brochure describing the Act and other background material was provided to each participant before the work group convened.

Title I provides emergency assistance to the metropolitan areas with the largest numbers of reported AIDS cases. These jurisdictions must establish an HIV Health Services Planning Council that includes representatives from community and hospital-based health care providers, community-based service organizations, community leaders, people with AIDS (PWAs) or HIV infection, and local and State governments. This council establishes priorities for distributing funds, develops a plan for organizing and delivering HIV health services, and assesses the efficiency of administrative mechanisms for rapidly allocating funds to the identified priorities.

The grant funds can be used for delivering or enhancing HIV outpatient and ambulatory health and support services, including case management and comprehensive treatment services and inpatient case management services that prevent unnecessary hospitalization and expedite discharge from inpatient facilities. Under certain conditions, funds may be used to meet personnel needs. Fifty percent of Title I funds is distributed by formula, and 50 percent through competitive grants. In FY 1992, \$119,426,000 was available under Title I.

Title II grants provide support to the States to improve the quality, availability, and organization of health care and support services for persons with HIV disease and their families. Each State is eligible for funds based on the number of reported AIDS cases for the two most recent fiscal years. The minimum Title II grant is \$100,000.

Title II grants may be used to:

- establish and operate HIV care consortia which provide a comprehensive continuum of care to persons with HIV disease and their families. The legislation requires States reporting one percent or more of all AIDS cases to use at least 50 percent of their funding to create and operate consortia in the areas of the State with the largest numbers of patients with HIV disease;
- provide home and community-based care for persons with HIV disease;
- provide continuity of health insurance coverage for persons with HIV disease; and
- provide HIV and AIDS treatments to prolong life and prevent deterioration of health.

The Act requires that 15 percent of grant funds be set aside to provide health and support services to infants, children, women, and families with HIV disease. Up to 10 percent of the total Title II appropriation may be used to fund Special Projects of National Significance (SPNS). In fiscal year 1993, \$11 million is available under SPNS. Approximately \$5.2 million of the SPNS funds will be used to reimburse dental schools for dental care provided to people with HIV infection who cannot pay for their dental care. The rest of the funding has been allocated to programs that demonstrate innovative approaches to HIV service delivery or serve hard-to-reach populations. Twenty-six SPNS grants were awarded in fiscal year 1992.

Each consortium funded by Title II must:

- identify populations and sub-populations of persons with HIV disease;
- conduct a needs assessment;
- develop a service plan, which includes agencies and community-based organizations with a record of HIV service;
- demonstrate that adequate planning has taken place to meet the needs of persons with HIV disease; and
create an evaluation process.

States with more than one percent of AIDS cases reported nationally must make resources available to match Title II funds. In FY 1992, \$94,704,522 was available for Title II.

Title III-b The Bureau of Primary Health Care administers this program. The grants from Title III-b provide direct funding to community primary medical care service providers, including migrant health centers and local health departments. Title III-b programs are required to include:

- HIV counseling and testing;
- outreach to individuals at risk for HIV disease; prevention counseling;
- case management; and
- the provision of early intervention services.

OTHER HRSA HIV/AIDS PROGRAMS

The *NIDA/BPHC initiative* is a demonstration grant program, administered by the Bureau of Primary Health Care (BPHC), that links HIV primary care to substance abuse treatment services. The program has approximately \$9 million in funding for fiscal year 1992 and currently serves 20 grantees.

Pediatric AIDS Service Demonstration Grant program provides HIV/AIDS health and social services to children with HIV/AIDS. It is administered by the Bureau of Maternal and Child Health and has approximately \$20 million in funding for fiscal year 1992.

The AIDS Education and Training Centers Program (ETC) administers 17 centers, funded in fiscal year 1992 to conduct HIV/AIDS clinical education for physicians, mid-level clinical providers, dentists, and other health care providers. The ETC program is administered by the Bureau of Health Professions. Approximately \$17 million in funding is available in fiscal year 1992.

The Facilities Renovation Program (1610-b program) has funded the renovation or construction of facilities to provide non-acute and long-term AIDS/HIV care. It did not receive a fiscal year 1992 appropriation. This program is administered by the Division of Facilities Assistance and Recovery in the Bureau of Health Resources Development.

Home Care and community-based HIV Service Demonstration grants were a one-time award made to States in fiscal year 1990 to provide care in the homes of people with AIDS.

Following Dr. Bowen's remarks, a participant reported that The National Congress of American Indians has con-

tracted with Support Services, Inc., to bring together tribal and urban Indian leaders and officials of the Indian Health Service and other Federal agencies to discuss AIDS issues and develop strategies for addressing them. Some funding is provided by the Department of Health and Human Services' National AIDS Program Office. The goal of this project is the identification of:

- HIV prevention concerns;
- treatment services;
- policy issues; and
- strategies to address the concerns.

II. Social and Cultural Context of Health Services

Throughout the day-and-a-half workshop, the participants discussed the social and cultural characteristics which distinguish American Indians and Alaska Natives. They emphasized that these characteristics are the context for understanding the factors that influence access to health care in American Indian communities. The participants described the diverse cultures, the richness of their heritage, and historical influences that have shaped the societies of First Nation peoples and which influence their view of health care. Further, they observed that outside agencies providing services, including BHRD, must acquire understandings of the local service area.

"...First, we need to be recognized as American Indians and Alaska Natives. People come from tribes. I am only as strong as the Mescalero Apache and that is true for each of you. We need to come together..."

American Indian societies are culturally distinctive, diverse, and complex, and their population is growing. One participant noted that the total American Indian population is growing twice as fast as the general population. The problems that face some American Indians are often due to low self-esteem and lack of trust of society's majority.

"We are long-suffering, patient, and polite. It's part of our culture to show respect. At the same time, it doesn't get us anywhere fast. It's not a matter of becoming impatient but of adapting."

The consequences of forced and voluntary acculturation to European-American ways have combined to undermine traditional tribal cultures. This has been achieved through the destruction of local economics, boarding school education, prohibitions against the speaking of American Indian languages, adoptions by European-American families of Indian children and discrimination.

"We need to empower ourselves by virtue of our status as First Nation citizens by remembering and reinforcing our identity. We have had European contact for 12 generations, but we've been here for 12,000 generations. This is where we get our ability to survive."

American Indians and Alaska Natives identify ethnically with a tribe, nation, or community. There is no single leader for all American Indians. American Indian tribes are autonomous political entities. Some tribes are Federally-recognized, i.e., have a government-to-government relationship with the United States. There are other tribes whose government-to-government relationship was terminated or who never concluded a treaty with the United States. Unrecognized tribe members do not generally benefit from IHS or other Federal programs for American Indians. There are approximately 500 Federally recognized tribes, Native villages and Native corporations in the United States. Over half of all American Indians live in urban areas. One quarter still reside on reservations, with the balance living in rural areas and the former Indian Territory (now the state of Oklahoma).

There is a lack of accurate demographic data about American Indians due, in part, to cycles of urban-rural migration. The migration flux causes census figures to portray inaccurately the nature and composition of American Indian communities. As one participant said, "It all depends on whom the census person met first, the mother or the father." The U.S. Census only counted as American Indian households where the head-of-household was Indian, leading to an undercount of Indian household members if the head of household was of another ethnicity. This exacerbates the difficult task of learning how many American Indians are affected by HIV.

Health data on American Indians are often incomplete representations of the nature and extent of the problems. For example, rates of HIV seropositivity are based on limited data, such as the number of STD clinic attendees, which is then used to generalize to the broader population. While the current numbers of American Indians with HIV infection seem low, the percentage of the American Indian population with HIV disease is probably underestimated. Rates of HIV seropositivity are based on limited data, usually from an IHS/CDC blinded seroprevalence survey of rural Indian pre-natal clinics primarily. Some clinics which treated STDs were also included, but most of the data they have is from the pre-natal clinic samples. The CDC conducted a study of the accuracy of reporting of AI/AN ethnicity on death certificates and in case management files in Seattle and Los Angeles. Rates of misreporting of AI/AN ethnicity for AIDS cases in those two cities were 75-100 percent. This is and has

been an ongoing issue for AI/AN not just in AIDS but all disease reporting. Several factors account for this, including poor data collection methods and under-reporting. The potential impact of HIV on First Nation communities is grave when under-reporting practices are added to inadequate HIV screening systems and high rates of sexually transmitted disease. This neglectful pattern has particular resonance for many American Indians, as it recalls to them the epidemics that decimated indigenous American populations from the time of early European settlement.

"...The Federal government has always been our big brother telling us how to spend money. They don't leave it up to us."

American Indian dependency on external programs and resources is a result of government funding perpetuating a "big brother" mentality that does not encourage sustainable programs operated by American Indians.

Participants described how this attitude leaves American Indian populations vulnerable to funding cuts and project cycles. Further, they added, funding cuts are often retroactive, which forces programs to try to operate with an inadequate cash flow. A participant offered an example of how past social welfare practices can have an impact on the next generation of programs. On the reservations, American Indians are accustomed to receiving some form of payment for participating in government activities. However, they are not paid to be tested for HIV and this some American Indians believe that HIV testing is not an important priority among social and health program managers.

According to one participant, "less than 0.5% of private sector money goes into American Indian communities." There is a myth that American Indians receive funding from their own Federal sources such as the Bureau of Indian Affairs or the Indian Health Service. Many Americans believe that "American Indians are taken care of."

"Indian people don't get money because public officials think they get it from welfare or 'Navajo Way' (an American Indian version of The United Way)."

Layers of bureaucracy often prevent funds from reaching those who need it. Typically, State governments, local governments, IHS Area Offices, and tribal leaders "filter" funding, which dilutes the impact of the program at the community level.

"...AIDS is not visible . . . It's new, it's on hold, it's happening somewhere else..."

American Indian and Alaska Native communities are not yet addressing HIV and AIDS. First, American Indians are still waiting for AIDS to be defined in Lakota (to be given a meaning in the local language) so that indigenous healing processes might be applied to it. Second, AIDS is only one of the many problems in most American Indian communities. Basic human needs, housing, food, and employment, have stretched American Indians resources to their limit. Third, an American Indian spokesperson has not been identified to make AIDS real for American Indian communities, as Magic Johnson has done for young people and African Americans. AIDS hysteria is high, in part because American Indians, like many others, do not understand how it is transmitted.

"...While treating a woman, a doctor learned that she was HIV positive and pregnant. He looked at her and stated, "You Indians are all alike! How can you bring a baby into the world with these factors?..."

Racism is an important complicating factor to consider when establishing HIV/AIDS service and prevention programs. The discussion reinforced the reality that American Indians continue to perceive HIV as "a white man's disease." This fact further exacerbates the racial oppression already felt by American Indians and widens the breach between the majority culture and American Indian cultures.

Racism and the preferences the majority society give to certain groups contribute to the distrust surrounding Indian-U.S. government interactions. The participants felt that institutional racism exists at the Federal, State, and county levels. "Multi-culturalism" is generally a government mandate, but often contributes to tensions among ethnic minorities. A participant added that many American Indians consider the majority culture's primary focus on African American issues as detrimental to American Indians. The result is that ethnic minorities compete with each other for limited resources. The addition of new Title I cities in fiscal year 1993 was cited as an example of "slicing the pie even thinner" and setting minorities against each other fighting over limited resources controlled by the majority society.

Another manifestation of racism, discussed briefly by the group, was the tension and conflicts that sometimes arise between "full-blood" Indians and "mixed-blood" Indians and between tribes recognized with Federal status verses non-Federally recognized tribes. The majority society's underlying values and policies that define who is, and who

is not, an Indian have contributed to inter-tribal and intra-tribal conflicts. In turn, these historical policies influence the availability and accessibility of care for American Indians, both rural and urban.

The Alaska Native communities are distinct among First Nation people because they are harder hit by the AIDS epidemic than other ethnic minorities. Before the Alaskan pipeline, there was no Federal designation of Alaska Natives, they were all "Eskimos." The United States Government policy which compensates Alaskan property owners near the pipeline also created the official ethnic group "Alaskan Native." Participants from Alaska, who call themselves Alaska Native, cautioned that to be effective, government programs must carefully consider the local tribes and organizations as defined by local people and not use group designations imposed from outside Indian communities. There are seven distinct indigenous nations in Alaska, with more than 500 identifiable tribes, linguistics and cultural features. This diversity calls into question the use of any single inclusive term.

"We are taught from the beginning who we are. When we say our name, everyone knows where we hunt and fish and pick berries. I try to listen to what's going on."

Communication between the institutions of the majority society, including those that deliver medical services, and the American Indian communities continues to be problematic. Several participants pointed out reasons that American Indians' participation in planning and managing grant programs may be compromised. Locally, American Indian expertise to write successful proposals and to conduct methodical research is in short supply. Where there is grant writing expertise, it has been in areas focusing on alcohol, diabetes, or nutrition. Thus, community, tribal, regional, and even national responses to AIDS/HIV funding announcements compete for the time of a few well trained and experienced individuals who write or do research on a wide range of health and social service issues. One participant, who has served on review committees for community-based grants commented, "It's heart-breaking to review grant applications. There's no comparison between a seasoned proposal writer's submission from an established agency and one from an American Indian reservation's community-based organization."

III. Barriers to Health Care and Support Services

"I live in San Francisco, but if I lost my job, I'd go back to my reservation at Gila River. When you get well, you go back to the city and your case manager doesn't know where you've been or what treatment you received."

Barriers exist at every level. Cultural, institutional, geographical, and political issues influence the form these barriers take. Misunderstandings about and ignorance of where and how Indians live and view health matters are barriers to care.

"Public agencies see American Indians as a small population with small numbers of affected individuals. They see Indian Health Service (IHS) as a magic word that when invoked brings resources to Indians. People assume that Indians get free everything."

Since 1955, the Indian Health Service (IHS), an agency of U.S. Public Health Service, has had responsibility for providing comprehensive, free-of-charge health services to American Indians who are members of Federally recognized tribes. In 1990, there were 127 service units located on or near reservations or in Alaska Native Health Corporations and Areas. The services offered vary greatly from one IHS facility to another. IHS clinics or hospitals located on the reservation are few. In fact, the IHS service areas designations are based on the American Indian population distribution in 1955. According to the 1980 census, only 25 percent of American Indians live on reservations. Seventy-five percent of American Indians live elsewhere in the United States, with a growing number living in cities. In the 1980 Census, 54 percent lived in urban areas.

Group members described the discrepancy between the supply of urban medical services and the demand by American Indians living in cities. There are only 28 urban clinics which offer medical services to American Indians living in cities. The services offered are not comprehensive and vary widely. If the services do not exist at a close-by urban clinic the only option is an IHS hospital or contract care service which require one to reside within service

boundaries and be a member of the tribe for whom that particular facility or service was established. These services may be hundreds, even thousands of miles away⁽¹⁾. There are only two IHS health units east of the Mississippi River and only one hospital providing comprehensive care. The hospital, in Cherokee, North Carolina, and a tribal run IHS hospital, located in Nashville, Tennessee, provide the only access to IHS services for Indians as far away as Washington, D.C., New York, and Maine. This leaves the majority of Indians without access to health care designed to meet their needs.

In some cities, IHS provides primary care to American Indians through contracts with health care agencies. Some agencies, which operate "638 clinics" (P.L. 93-638) are Indian-owned and operated. Historically, urban Indians have experienced difficulty and discrimination when using these agencies. Consequently, they decide to return to their reservation when ill, thus interrupting treatment and continuity of care. In addition, the funds to operate urban clinic programs which provide specialty services such as HIV-related care, are limited. Another participant observed that each IHS facility prioritized its use of contract care funds differently, and HIV/AIDS is usually not a top priority.

Often, IHS health care facilities and contract services are not located near the areas of high HIV-prevalence. The placement of IHS health care facilities is based upon census information from the 1950's when very few Indians lived in urban areas. Thus, IHS clinics are primarily concentrated in rural, reservation settings. However, American Indians with HIV live primarily in cities. Therefore, programs based on where Indians lived 40 years ago do not support the needs of Indians in cities. The discrepancy between the historical resource allocation plan of the 1950's and the contemporary population is a major obstacle to American Indians receiving comprehensive, appropriate health care wherever they live.

A recent (1991) IHS program has improved availability of HIV/AIDS medications for those in treatment. Under this program, an IHS facility can request medication from a central IHS warehouse and have it shipped, overnight, to a hospital depot or directly to an individual. There are some difficulties, such as a cumbersome reimbursement process. IHS officials are working to solve the existing problems.

(1) Evaluation of Potential Site Locations for New Urban Indian Health Care Programs and Identification of Urban Indian Health Programs Pursuing JCAHO Accreditation. Unpublished Manuscript American Indian Health Care Association, September 1989.

"Infected folks have to feel safe in their own community. We are all a family. In Alaska, distance is a real problem. I want to be taken care of by my own people as I get sick."

The American Indians and Alaska Natives live in every State of the United States, making a centralized system of health care delivery difficult. Residing in rural areas, on reservations and in cities, each American Indian group has its own cultural traditions. In Alaska, we mistakenly refer to the "Alaska Native." There are, however, significant language and cultural differences among the indigenous Alaskan populations. Effective service delivery must recognize these variations and take them into account. For example, within Alaska, there are profound differences among urban, rural non-reservation, and reservation settings regarding utilization of local services. Geographic barriers and political and institutional factors also vary in these settings.

Native peoples in Alaska have a seasonal economy based on fishing. It is difficult, therefore, for inhabitants to leave their homes during the peak fishing season to go for health care that may be hundreds of miles and several days journey from their home. In most of Alaska, transportation poses a nearly insurmountable barrier to receiving health care. Three urban clinic sites as well as Health Corporation facilities provide care to the entire State. Thus, individuals seeking health services frequently need temporary housing because they cannot return home the same day. While the transportation problem predates HIV/AIDS, it presents special challenges for providing a continuum of care for people with HIV infection.

Limited telephone communication seriously effects the use of health services including HIV care. Many Alaska Natives either do not have a phone or share a party line which makes it difficult to schedule appointments, report laboratory results, answer questions about treatment or make follow-up calls. Medical confidentiality is difficult, if not impossible, when telephones are in such short supply and radio must be used. One participant commented: "Confidentiality is our main concern. Village people are afraid of what people will say if they find out they've been tested for the AIDS virus."

In urban areas, discrimination toward or intolerance of homosexuals presents problems for "the middle-minded" or the "two-spirited." In some American Indian cultures, these

terms are used to describe people who have sex with others of the same sex or whose social role is different from the biological gender of that individual.

After exploring the issues surrounding the barriers to care, the discussion focused on possible solutions. Participants expressed interest in a system or "network" that would expedite the distribution of information. The objective of an "ideal" network of centralized American Indian-specific information would be to improve care and access to care by providing information to all care providers, including IHS doctors. It would, for example:

- collect and standardize data from all case management sites;
- provide liaison to government agencies;
- announce new treatments, and discuss prevention; receive technical assistance from HRSA;
- provide a menu of complete services;
- provide linkages and training to AIDS ETCs; and
- identify funding sources.

The workgroup recommended that a pilot project to support such networks should be developed and funded through SPNS and Title II State consortia funds. The participants recognized several significant restraints to such a network, including the availability of computers and the cost of training and software.

"We have a history of bad experiences with the medical system, so people often do not access care until the last minute."

American Indians often distrust health clinics and biomedicine. To understand how American Indians perceive AIDS/HIV, it is important to look at the current epidemic in the historical context of relations between immigrating European societies and the indigenous societies of the Americas. Group members recounted a historical legacy of mistrust since Europeans came to the Americas. This legacy includes the distribution of blankets infected with smallpox, forced migration in the winter, and the introduction of alcohol, along with policies of dependency and breeches in agreements with the sovereignty of First Nations. Among some indigenous peoples, AIDS/HIV has become associated with the destruction of their cultures.

Further discussion called attention to racism. Ignorance of Indian values and practices causes Indian patients to feel uncomfortable and, often times, totally alienated.

"The traditional healing approach does not take the microscopic approach and take the person apart. I have to start by putting the person back together."

The participants briefly discussed American Indian healing practices and its relation to HIV care seeking. They confirmed that indigenous healing is a fundamental component of many American Indians' lives and suggested that promoting access to local healers and healing ceremonies can be an important complement to biomedical treatment. The sweat lodges and sun dances, where people participate in sacred ceremonies, are important and carry spiritual meaning for American Indians with HIV/AIDS. An appropriate healing practice for one tribe may not be for another. For some people, indigenous medicine may be a critical and central component of their lives. For others, their religious practices do not include healing ceremonies as part of their spiritual life. Still others combine European and American Indian spiritual practices. And finally, some American Indian healers do not yet know about HIV.

"In South Dakota, the tribal government versus the State government versus the Federal government is a barrier. We became associated with ACT-UP."

The controversy over State government recognition of American Indian citizens and sovereignty creates funding difficulties. The fact that American Indians are citizens of their tribal nations and of the United States presents unique government-to-government problems. Often, American Indian patients fall between the cracks, and have access to neither State nor Federal programs. Some State governments do not feel obligated to provide services to the residents of autonomous reservation who pay "no taxes." However, up to 75 percent of American Indians live off the reservation and pay State taxes. In a Montana case involving the IHS vs. the State, the courts ruled favorably for the IHS and the State was required to pay for health services delivered to American Indians. Participants described instances in which tokenism is also a problem in government-to-Native-peoples relations. States claim to treat American Indians, but actually only serve a small number.

"You'll find States that find one American Indian and serve him and say "we fulfilled our obligation."

The many levels of bureaucracy also reinforce barriers. These include various Federal agencies, the Bureau of Indian Affairs (BIA), the IHS, State governments, local governments, and the tribes. Funds often do not reach the communities. In addition, an American Indian seeking health care may be sent from one jurisdiction to the other and never receive the care they need.

IV. Behavioral and Organizational Factors

Effective evaluation of health services must contain analyses of the attitudes, practices, and procedures of current health service agencies and of the perceived gaps in health care delivery and related support services as reported by American Indians and Alaska Natives who use them.

The participants cited the following essential factors:

- fear of biomedicine;
- the stigma associated with AIDS; and
- the attitudes of health care providers.

Several factors make up the decision to seek treatment, including: distance, previous experience as a patient/client, financial burden, and perceived need. In addition, the decision to seek health care reflects whether a person recognizes the condition as an illness treatable by biomedicine and whether he/she places health as a high priority. For example poor people and women often place seeking care for themselves below subsistence needs such as food, housing, employment, and the welfare of their children. Added to this is the, often, unsatisfactory treatment by biomedical practitioners, the loss of confidentiality about their illness and the stigma attached to seeking HIV care.

TREATMENT ISSUES

"We educate people, but if behaviors don't change, people are not served. The big barrier is getting people to acknowledge the problem."

The critical need for HIV prevention education as an essential element of effective service provision was an underlying theme throughout the workshop. The HIV/AIDS epidemic among American Indians and Alaska Natives is in its early stages. To be effective, services must include HIV prevention and treatment information. Poorly designed prevention messages undermine service delivery efforts. In addition, "providers have to look like the community they intend to serve."

HIV/AIDS education also has an impact on service delivery. Poor communication and misinformation about HIV—how it is transmitted and whether it is treatable—often underlie the barriers to individuals seeking care in a timely fashion. One participant described a woman she knew: “She learned that she should get tested every six months, and she did just that, but nowhere along the line did anyone teach her how to keep from getting HIV infection.” The message has not gotten across to many people that this disease cannot be treated like syphilis and gonorrhea. As one participant said, “If you don’t have education, people don’t get tested. If they don’t get tested, you don’t have numbers. Without the numbers, you don’t get money.” But, “I don’t want to win the numbers game in order to get more money for HIV prevention education.”

In Alaska, one education/prevention program has two trainers, a number that is inadequate for the territory involved. Another participant in the meeting noted that it was difficult to talk about HIV on reservations and in rural areas because of the irrational fears people have based on misunderstandings. One participant related an anecdote to illustrate the fear within one community. A person from an Indian health care organization came to a village to talk about HIV prevention. People who did not attend and the people who did go both accused each other of having AIDS. The participants identified characteristics of an outreach team, including:

- multidisciplinary (clinical and social services) teams that go into villages;
- separate and distinct education messages for men and women that address issues of denial, substance abuse and HIV, and sexual addiction;
- prevention messages to address HIV and STDs, together, due to the high rates of STD cases among American Indians.

The need to inform the public is essential. A group called “Positively Native” provides general HIV information and clinical trial options. Education and services can be delivered through the Community Health Representatives (CHR)², the people on the reservations and in the rural areas who have the credibility to reach that community.

The discussion highlighted a dilemma in increasing the treatment information sources and maintaining cultural

relevance. Group members explored the advantages and disadvantages of training Indians in their local communities to be outreach workers and compared it with building the capacity of non-Indian agencies to interact competently and effectively with Indians about HIV matters. "By the time we educated them about American Indians, years will be lost." Their materials do not address the cultural issues and do not include information on traditional healing or other American Indian cultural practices. Non-Indian agencies delivering care and education to American Indians need to ensure that their staff and messages are culturally competent, literacy appropriate, and locally relevant.

"Case management is often the critical ingredient to get people in the door for services, but it can't just end there. We have to be sure people, in fact, get the services and are not simply sent elsewhere."

Case management is a new concept for American Indians, especially in rural areas. Through assessment, referral, and follow up, case management can help American Indians access care, counseling, testing, treatment, housing, and other important resources. Existing models need to be strengthened to respond effectively to American Indian cultures and other issues, such as distance, and multiple-diagnoses. It is crucial that American Indians have input at every stage. Involving American Indians in the process can help identify who can be served, staffing needs, and other specific issues for training. Follow-up is critical so that individuals maintain contact with the health care system. Families and communities who may be caring for several individuals—often concurrently—also need education to know that services and case management exist and can help. It is essential for outreach workers to inform the community about the availability of services.

"HIV affects every aspect of our lives; we can't deal with it in a separate box, we also must deal with drug abuse, alcohol, sexual abuse, all the issues."

Comprehensive, integrated service delivery that also is culturally competent does not exist in rural areas. In most places, a client faces a maze-like health care system which is often fragmented. It is very common to travel to one facility

2 Community Health Representatives (CHR) are paraprofessionals who work under the supervision of a family nurse practitioner or other health professional. CHR's perform such duties as : counseling, education and assist medical providers. In Alaska, the term Community Health Aides (CHA) is used to describe similar paraprofessionals.

for maternal/child care, to another for testing, and still another for primary care. There is also a lack of childcare and temporary housing for those who travel to health care services from rural areas.

Participants suggested evaluating the "one-stop shopping" model with support services as a strategy to improve services. For example, the model would provide childcare for families and comprehensive services for the multiple-diagnosed (mental health, substance abuse, STDs and HIV). Where the needs indicate, the services also would include indigenous healers, and other cultural appropriate support. Staff training, records management procedures, and well-designed waiting room areas are essential details that can make the difference between a facility that users perceive as comfortable, welcoming and safe and one that is "not where I want to go."

Attention to alcohol and other drug abuse problems in the American Indian population is a priority for prevention/treatment programs. Historically, alcoholism has been, and continues to be, a major problem. As such, it drains resources from other issues—including HIV/AIDS—and creates the challenge of serving individuals with several diagnoses. IHS staff do not have the resources to provide comprehensive substance abuse treatment and recovery care.

Complicated forms and procedures for medical and social assistance frustrate applicants and providers. Often, the effort to apply is not worth the small reimbursement. Having a social service staff member help the patient "navigate" the bureaucracy was mentioned as a successful strategy. Referred to as patient advocates, or simply friends, these individuals can increase the likelihood that an individual will keep appointments, take medications as prescribed, and benefit from treatment. This strategy, however, has of *limited* value when staff resources are *limited*.

"Indian people are not participating in Title I planning councils or Title II consortia. Sometimes there is tokenism. We need you [the Federal government] to sensitize the top, we need to work from the bottom."

There are few American Indians or Alaska Natives represented on Title I planning councils or participating in Title II consortia. Therefore, there is inadequate understanding of the needs and effective strategies for delivering services to American Indians. Some participants viewed this

as an example of the perennial neglect of American Indian health service needs. "Our needs fall between the cracks." Many State organizations are just beginning to become aware of American Indian HIV services needs. Many participants, involved in tribal activities and knowledgeable about the Ryan White CARE Act, observed that to deliver effective health care to American Indians, there must be improvement in the existing interactions between American Indians organizations and the Title I planning councils and Title II providers.

The participants expressed a growing concern that as more cities qualify for Title I funds, the same level of total Title I funds will be stretched among more grantees with less available to each. Also, the proposed CDC change in the definition of AIDS will add more individuals to the count and thus more cities will be eligible for the same pool of funds.

PSYCHO-SOCIAL ISSUES

"People have no trust in the protection of confidentiality."

Confidentiality is an important underlying issue in dealing with HIV among American Indian populations. In the closely-knit and often small American Indian communities of 1,000 inhabitants or less, confidentiality is a problem. Lack of confidentiality discourages American Indian populations from being tested for HIV and seeking medical treatment. Releasing geographic information that identifies the location of HIV disease also can result in a breach of confidentiality in small communities. Paradoxically, HIV/AIDS dedicated clinics while intending to improve the quality of care for those with HIV infection, may have a negative effect on promoting confidentiality.

"Our families need to learn that we have to deal with the disease. We can't wait to see how we feel about it, because all the virus wants is a warm body."

The importance of families (including non-traditional families) and traditions of support must be reinforced. Reducing the lack of interest and understanding of family support by health care staff is a key element in addressing this problem. Home care is an important concept to American Indians. And, given the distances people must travel to receive care, home care by family is ideal when medically appropriate.

"Our people do more time in institutions and corrections than any other group."

The high level of incarceration among American Indians exacerbates the problems of prevention and health care delivery. HIV is a problem for all incarcerated populations, but takes an added toll on people who are less able to blend into society and tap its resources after release or parole. The exiting post-release program are not based on American Indian values and thus do not attract those who need them.

ORGANIZATIONAL CONCERNS

Providers serving Indians are not knowledgeable about the provisions of Titles I and II. Therefore, they miss the opportunity to inform their patients of available services, such as free drugs. American Indian agency administrators are reluctant to seek CARE Act funds, because they have many other overwhelming issues to deal with, including limited staff, the stigma of HIV, homophobia, and confidentiality issues.

SUMMARY OF ISSUES

A synthesis of the two-day workshop identified the following issues and trends. Each was defined as an issue that requires attention to improve the quality of health care delivery.

1. need to create integrated, comprehensive and coordinated services for individuals with several diagnoses (STDs, HIV, mental illness, and substance abuse);
2. need to create regional service networks, like the Seattle model of People of Color Against AIDS Network (POCAAN);
3. need for health care agencies and staff to respect patient confidentiality and adopt confidentiality protection procedures;
4. need to create/adapt American Indian-specific case management models that address the social and cultural features of American Indian people;
5. need to educate planning councils and consortia about the service and treatment needs of American Indians in both urban and rural areas including the fact that Indians migrate between urban and rural areas;
6. need to explore the possibility of funneling tribal monies through community-based organizations (such as white,

- gay-based organizations) to improve access for American Indians not residing near their tribal home;
7. need to increase State Title II funding to meet the expanding service delivery demands of American Indians;
 8. need to develop literacy appropriate and culturally competent treatment social support services;
 9. need to provide services for individuals with varied sexual orientations, such as the "two-spirited" or "middle-minded" (trans-sexuals, individuals who assume the social and sexual roles of the opposite gender);
 10. need to address issues of sexuality, including the effects of early sexual activity, sexual abuse, and homophobias;
 11. need to work with other minority groups to assure that American Indians are part of the planning process;
 12. need to use program funds for rural patients transportation expenses, particularly in Alaska;
 13. need to educate tribal leaders and community leaders about HIV as part of the efforts to gain their support for HIV programs;
 14. need to identify and support people in the tribes and communities who are willing to or play a leadership role in support of HIV programs.³

V. Issues, Concerns and Recommendations

Work group participants identified the following issues, concerns, and recommendations as ones that could improve the effectiveness of the Ryan White CARE Act. These have been brought to the attention of the Division of HIV Services and the AIDS Program Office who will work with individuals and agencies to address the issues. Some of these topics have technical assistance implications and are referred to in that section.

SPECIFIC ISSUES AND CONCERNS IDENTIFIED FOR FOLLOW-UP BY BHRD

National Information and Referral Network

- Develop and manage an American Indian/HRSA system for disseminating timely treatment-related and funding information through a comprehensive national database. This would enhance the capacity of American Indian organizations and providers to respond to initiatives of funding agencies and to share information about HIV care with each other.
- Train clinical providers serving American Indians in both IHS and non-IHS agencies, through AIDS ETC continuing education programs.
- Develop an American Indian advisory group to HRSA, based on the existing model of the CDC National Minority organization. The American Indian group would inform HRSA of activities on the front lines and provide an opportunity for face-to-face exchange and informal networking among group members.
- Conduct drug trials such as for AZT and dDi to determine the effects on American Indians and Alaska Natives.
- Increase State Title II funding allocations to meet the needs of American Indians with HIV infection.
- Title II should address the problem of geographical differences in delivering services. For example, one

planning meeting in a large rural area is not sufficient to address the concerns of a widely dispersed population.

- Prevention messages targeted to teenagers are critical. On one reservation, one participant reported that of nine HIV/AIDS cases diagnosed, six were adolescents.
- The seasonal migration among some American Indians is a significant factor in obtaining high quality and continuous health care, especially for those with HIV infection.
- States Title II administrators and planners should pay more attention to the distinctive problems faced by American Indians with HIV infection.
- American Indian groups (tribal leaders, community-based organizations, AIDS service organizations, etc.) must become educated about the Title I, II, and III application requirements.
- The Request For Application (RFA) process should be used instead of the Request For Proposal (RFP) process, so national and community-based American Indian agencies have access to technical assistance before applying for funds.
- More time is needed between the issuance of an RFA and the deadline for response to allow community-based agencies to respond.
- Because of the decreasing and restricted funding, education, prevention and treatment programs are being pitted against each other.
- Enhance coordination of policies and procedures at the Federal level between Congress and agencies within the Department of Health and Human Services. Improve linkages between the Centers for Disease Control and Prevention (CDC), HRSA, IHS, and the National Institutes of Health (NIH) to improve the accuracy of racial/ethnic survey data. This is an essential element in policy formation and program management.
- American Indian participation should be mandated at the State and local level as part of an approach to reduce racism and barriers to HIV care encountered by American Indians.

VI. Technical Assistance Issues

The following issues were identified as ones the participants felt needed technical assistance from the BHRD. The Division of HIV Services will be responsible for following up these issues:

- Assist with grant applications completion. Adequate notice of the availability of funds must be provided to American Indian organizations. Indian agencies miss opportunities because they receive grant application announcements within weeks of their submission deadlines thus making the necessary deliberations impossible.
- Assist in addressing issues of representation and access to the planning process:
 - Title I councils need information on the impact of HIV on American Indians in their cities and on strategies for effectively reaching them with services.
 - Title II should address the problem of geographical differences in delivering services.
 - States should pay more attention to the distinctive problems associated with Title II funding and American Indians.
 - American Indian groups (tribal leaders, community-based organizations, AIDS service organizations, etc.) must become educated about the Title I, II, and III application requirements.
- Build assertive communication skills to help American Indians deal more effectively in majority culture arenas.
- Develop an information and dissemination plan to familiarize tribal leaders, local health officials, and service organizations with the Ryan White CARE Act.
- Develop and implement comprehensive, culturally appropriate, and literately appropriate HIV / AIDS treatment program that can be adapted to the specific needs of American Indians.

- Assist with building coalitions with other ethnic minorities, ASOs and other relevant agencies.
- Assist with developing effective subcontracts for referral agreements and evaluation designs where local expertise does not exist.
- Assist with advocacy, including informing the States of the obligation to include representatives of all affected populations on the Title II Ryan White planning councils

VII. Recommendations for Evaluation Studies

The participants in the workshop formed four groups to develop and recommend plans for education projects. Recommended project areas included:

- decision-making;
- case management, treatment, and indigenous medicine; special populations; and
- a national information and referral network.

Each group then reached consensus on the specific recommendations for each subject area, as described below.

- Evaluate existing comprehensive systems of care (such as treatment for substance abuse, sexual addictions, and STDs), including indigenous medicine therapies to identify factors that make them effective;
- Evaluate existing case management systems to determine their applicability to the needs of American Indians with HIV;
- Evaluate smaller pilot projects that foster coalition-building among American Indians and provide a safe, comfortable environment for American Indians with HIV;
- Evaluate programs that emphasize a continuum of care and address issues such as improved nutrition, medication, and clinical management;
- Evaluate programs that encourage the will to live in individuals with HIV by using PWAs as counselors;
- Evaluate the degree to which access to HIV care by American Indians is improved when program staff is culturally competent;
- Evaluate programs with components that incorporate indigenous healing (meditation, prayer, sweats) as a key part of therapy and case management;
- Evaluate characteristics of mental health services that are effective in improving access and continuous use by being sensitive to American Indian needs, in general,

and the psychosocial needs of HIV-affected persons, in particular;

- Evaluate the key factors in reducing suicide in American Indians with HIV disease and increasing their use of services;
- Evaluate programs and intervention designs that effectively improve access to care by developing community and family support skills;
- Evaluate how to improve access to care through expanding the dissemination of AIDS Clinical Trial Groups (ACTG) research to all communities including American Indian communities.

SPECIAL SUB-POPULATIONS

The needs of several sub-populations within American Indians were highlighted:

- More training and education should be provided to care providers in the areas of substance abuse and women's issues. These issues appear in different forms in American Indian communities and, thus, may require different strategies.
- Counselors need to be trained in issues of sexuality. This includes American Indian counselors who often have their own biases and preconceptions.
- Respite care, childcare, and care for asymptomatic women are needed.
- It is necessary to understand the environment and lifestyle of seropositive American Indians and provide a non-biased approach to meeting their needs.
- Adolescent women need culturally competent, literacy appropriate, and age-appropriate counseling.³

3 Due to limited prevalence studies, and the misclassification of Indians and rural urban residence, it is likely that the number of Indians with HIV infection has been underestimated

Appendix

BUREAU OF HEALTH RESOURCES DEVELOPMENT
WORK GROUP ON NATIVE AMERICAN INDIANS
AND ALASKAN NATIVES
ACCESS TO HIV CARE

Embassy Suites Hotel Crystal City, Virginia
April 28 - 29, 1992

AGENDA

Tuesday, April 28

- | | |
|-----------------------|---|
| 2:00 p.m. - 3:00 p.m. | ARRIVAL AT EMBASSY SUITES |
| 3:00 p.m. - 6:00 p.m. | AFTERNOON SESSION |
| | Welcome and Opening Remarks |
| | Format for next day's work session |
| | Introductions of Participants |
| | Discussion of Ryan White CARE Act
and Barriers to HIV Care |
| 6:30 p.m. | DINNER (AT EMBASSY SUITE) |

Wednesday, April 29

- | | |
|--------------|---|
| 8:00 - 8:30 | CONTINENTAL BREAKFAST
(Hotel Lobby Level) |
| 8:30 - 12:00 | Discussion of Barriers to Care
and Drafting of Evaluation Projects |
| 12:00 - 1:30 | Lunch (in meeting room) |
| 1:30 - 3:30 | Complete Drafting of
Evaluation Projects |
| 3:45 - 5:15 | PROJECTS SUMMARIES |
| 5:15 - 5:30 | Wrap-up and Thanks |
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Appendix

Native American Indians & Alaska Native Work Group on Barriers to HIV Care

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